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Published article:

Bryant, LD, Green, JM and Hewison, J (2010) *The role of attitudes towards the targets of behaviour in predicting and informing prenatal testing choices*. Psychology & Health, 25 (10). 1175 – 119.

<http://dx.doi.org/10.1080/08870440903055893>

Bryant LD, Green JM and Hewison J. (2010) The role of attitudes towards the targets of behaviour in predicting and informing prenatal testing choices *Psychology & Health* 25: 1175-1194.

The role of attitudes towards the targets of behaviour in predicting and informing prenatal testing choices

ABSTRACT

Research considering the role of attitudes in prenatal testing choices has commonly focused on the relationship between the attitude towards undergoing testing and actual testing behaviour. In contrast, this study focused on the relationship between testing behaviour and attitudes towards the *targets* of the behaviour (in this case people with Down syndrome (DS) and having a baby with DS). A cross-sectional, prospective survey of 197 pregnant women measured attitudes towards the targets of prenatal testing along with intentions to use screening and diagnostic testing, and termination of an affected pregnancy. Screening uptake was established via patient records. Although attitudes towards DS and having a baby with DS were significantly associated with screening uptake and testing and termination intentions, unfavourable attitudes were better than favourable ones at predicting these outcomes. For example, in the quartile of women with the ‘most favourable’ attitude towards people with DS 67% used screening although only 8% said they would terminate an affected pregnancy. Qualitative data suggested that not all women considered personal attitudes towards DS to be relevant to their screening decisions. This finding has implications for the way in which informed choice is currently understood and measured in the prenatal testing context.

Keywords: Down syndrome; attitudes; informed choice; prenatal testing

INTRODUCTION

Understanding how to facilitate informed choices in healthcare settings has increasingly become a focus of research in those taking a psychological perspective on health behaviour. There are many definitions of informed choice but it is generally agreed that as well as being based on good quality information the choice should accord with a person’s attitudes and values (Bekker *et al.*, 1999; Marteau, Dormandy, & Michie, 2001). The need for informed health choices that are consistent with personal values is especially important where each option in a ‘choice set’ may have life changing consequences for the individual and their family. This is the case with prenatal testing decisions. Prenatal tests for Down syndrome are now offered as a routine part of antenatal care in many countries. Diagnostic tests which offer high rates of certainty that a

pregnancy is affected by Down syndrome, for example amniocentesis and chorionic villus sampling, all carry a small risk of miscarriage. Therefore it is usual practice to offer a screening test to identify women at higher risk of having an affected pregnancy. Screening can be done using biochemical tests on a maternal blood sample, via ultrasound scanning, or increasingly, a combination of both technologies. Diagnostic tests are then generally only offered to those deemed to be in a higher risk group. If a diagnostic test identifies that the foetus has Down syndrome, women are usually offered the option of termination of pregnancy. The study reported here considers the role of attitudes towards the ‘target condition’ of Down syndrome in predicting and informing prenatal testing choices.

An attitude can be said to be an evaluation of an object as favourable or unfavourable (Eagly & Chaiken, 1993). Attitude objects may be very broadly split into the two categories of targets and behaviours. For example, a person might hold an attitude towards having a baby with Down syndrome, and they might also hold an attitude towards having a prenatal screening test for Down syndrome. While the two attitudes may well be linked they are conceptually distinct. The former would be an attitude towards a target, and the latter would be an attitude towards a behaviour *directed* at a target (Eagly & Chaiken, 1993). In health psychology, much of the research into the relationship between attitudes and behaviour has been informed by ‘rational’ expectancy-value models most notably the Theory of Reasoned Action (TRA) (Ajzen & Fishbein, 1980) and the Theory of Planned Behaviour (TPB) (Ajzen, 1991) both of which focus on predicting behaviour via attitudes towards the behaviour rather than attitudes towards the behavioural target.

The TPB has been applied to the topic of prenatal screening, most recently in the development and application of the Multi-Dimensional Measure of Informed Choice (MMIC) (Dormandy, Hankins, & Marteau, 2006; Marteau *et al.*, 2001). In addition to assessing screening related knowledge the MMIC measures a person’s attitude towards undergoing a screening test, using the *attitude towards the behaviour* as a proxy for the values component of an informed choice. The developers of the measure have argued that attitudes towards undergoing screening incorporate wider values, such as a person’s perceived ability to parent a child with Down syndrome (Marteau *et al.*, 2001). The MMIC measures attitude towards undergoing screening via six items based on previous implementations of the TPB in health related situations, for example “for me, having the screening test for Down syndrome when I am 15-16 weeks

pregnant will be a good thing/not a good thing, beneficial/not beneficial, harmful/not harmful” (pg 62, Dormandy *et al*, 2006). Responses to these items are used to calculate an overall attitude towards undergoing screening. An informed screening choice is characterised as one where screening related knowledge is good and attitudes towards undergoing a screening test (favourable or unfavourable) are consistent with screening behaviour (undergoing screening or not undergoing screening) (Marteau *et al.*, 2001).

The way in which attitudes towards targets predict seemingly related behaviour has received much less attention in health psychology, yet this approach is pertinent when considering influences on prenatal testing uptake as tests are developed with a very specific ‘target’ in mind. Fazio proposed a model of the link between attitudes towards targets and target related behaviour, which has been presented as an alternative to the expectancy-value models (Fazio, 1986, 1995). In this model, an attitude towards a target (for example, an unfavourable attitude towards having a baby with Down syndrome) is said to be automatically activated in the presence of cues (for example, the offer of a screening test for the condition) related to the attitude object. Once activated, the attitude biases the processing of information relating to the target, which in turn guides how the event is defined (for example, seeing the offer of testing as a positive event because it increases the probability that the birth of an affected child can be prevented). From this definition of the event, the behaviour (in this case acceptance of testing) ‘simply follows’ (Eagly & Chaiken, 1993). In persons whose attitudes are too weak to be automatically activated, or the cues associated with the target are absent (for example, it is not made clear that a test is for Down syndrome) ‘normative factors’, for example, the behaviour of others or advice from health professionals, would be the main guide to testing behaviour.

The work of Fazio and colleagues suggests that examining how attitudes towards the targets of prenatal testing behaviour may influence testing decisions may be of value. However, while there has been a significant amount of research considering women’s attitudes towards undergoing prenatal testing (for a review see (Green, Hewison, Bekker, Bryant, & Cuckle, 2004)) there has been very little which examines their attitudes toward the tested-for conditions. This is surprising as a major factor in the decision to terminate a pregnancy for abnormality is known to be the perceived severity of the condition diagnosed (Evans *et al.*, 1996; Statham, 2002). In a study which investigated women’s (hypothetical) prenatal diagnosis and termination intentions for 30 different conditions, perceived severity of the condition predicted these

intentions but a considerable amount of individual variation was identified (Hewison et al., 2007). This suggests that perceptions of the condition being tested for should be important in informing women's actual prenatal testing decisions. Research on attitudes towards parenting a child with a disability has found that the perceived lack of rewards associated with parenting an affected child predicts intentions to using prenatal diagnosis (Lawson, 2006). Holding clear views about the acceptability or non-acceptability of the birth of a disabled child has been shown to ease prenatal test decision making (St-Jacques et al., 2008). Qualitative work has also shown that women may talk about their experiences of disabled people and their views on parenting a disabled child when being interviewed about why they accepted or rejected prenatal testing (Etchegary et al., 2008; Leuzinger-Bohleber, Engels, & Tsiantis, 2008; Lewando-Hundt et al., 2006).

Down syndrome has been and continues to be a central focus of prenatal testing technology; it is also one of the most common and recognisable causes of learning disability. Despite this, a systematic investigation of how attitudes towards the condition predict and inform prenatal testing and termination decisions is missing from the literature. The main aim of this study was to investigate how in pregnant women, attitudes towards Down syndrome related to screening uptake and towards intentions to use diagnostic testing and termination for the condition. In particular, it considered attitude towards people with Down syndrome as well as attitude towards having a baby with Down syndrome as one was thought to be likely to inform the other.

METHOD

Design

A cross-sectional, prospective survey was conducted using a self-completion questionnaire administered to pregnant women who were to be offered second-trimester prenatal screening for Down syndrome.

Setting

The study took place in the antenatal clinic of a hospital in an urban area of Northern England in 2000/2001. The hospital was selected because at the time of the study it was the only one in the region offering serum screening to all women regardless of age; this avoided potential bias in an age restricted population.

Antenatal care was centrally organised and clinic-based midwives carried out all the booking appointments.

A second trimester serum-screening test ('triple test') was offered to all women who attended for booking at

18 weeks gestation or earlier. First trimester screening was not available at the time of the study. If the woman agreed to have the triple-test a separate appointment was made for her to have blood taken at 15-18 weeks gestation. At the time of the study, uptake of serum-screening at this hospital was around 63%, which was in line with the average uptake for the UK as a whole (Dormandy, Michie, Weinman, & Marteau, 2002). Approval for the research was obtained from the appropriate Local Research Ethics Committee and the Research and Development Quality Group of the NHS Trust where the study was to be carried out.

Procedure

The midwives conducting the booking appointments invited women who met the study inclusion criteria to participate in the research; those who opted in were given an information pack and questionnaire. Potential participants had to be 18 years or older and of 14 weeks gestation or less at the time of booking. This was to give women time to consider any issues raised by the study and the opportunity to discuss them with their midwife and partner. The women were asked to complete the questionnaire at home and return it by post before their next antenatal visit. Completed consent forms were forwarded to the Clinical Midwifery Leader who used patient records to establish screening uptake. A list of test uptake status by questionnaire identification number was then sent to the researcher. Overall uptake figures for the study period were obtained from the Immunoassay Laboratory responsible for processing the tests.

Participants

Over the recruitment period up to 840 questionnaires were distributed to eligible women and 200 questionnaires were returned to the researcher (estimated minimum response rate of 24%). Two questionnaires were unusable due to lack of data and one was from a woman younger than 18; the final sample size being 197 women. Possible reasons for, and implications of, this lower than expected response rate are considered in the discussion, however, it is very likely that not all questionnaires were distributed, thus artificially lowering the response rate.

Materials and measures

An A5 size 20-page questionnaire was used as the data collection tool (please see the online version of the article for the full questionnaire). The questionnaire was developed for an average reading age of 11 years

(Flesch-Kincaid Grade Level 5.9). The first section of the questionnaire provided a basic explanation of screening and diagnostic tests to ensure that women unfamiliar with antenatal testing could still complete the questionnaire. Attitudes towards the availability of serum screening, diagnostic testing and termination of pregnancy were measured along with intentions to use screening, diagnostic testing (in the event of a positive screening result), and to terminate a pregnancy affected by Down syndrome. Where permission was granted, patient records were used to establish whether the participant subsequently had had a serum screening test or not. Basic socio-demographic and obstetric data were also collected including age, educational achievement, religion, current gestation and parity (number of live born children). Age, education and religiosity are known to relate to attitudes towards prenatal testing and termination (Furr & Seger, 1998; Green, Snowdon, & Statham, 1993).

Attitude towards having a baby with Down syndrome was measured on a nine point scale, with one being anchored as 'extremely bad' and nine as 'extremely good'. To measure 'attitude towards people with Down syndrome' open-ended measures of attitudes were used based on those previously developed to assess attitudes towards minority groups, including people with disabilities (Esses & Beaufoy, 1994; Esses, Haddock, & Zanna, 1993; Kiger, 1997). Measures of four different components considered central to understanding attitudes towards minority groups: stereotypic beliefs, symbolic beliefs, affect, and behavioural information (past experiences) (Haddock, Zanna, & Esses, 1994) were employed. Using the individual component scores an overall attitude score was then calculated. These open-ended measures have been shown to be reliable and valid measures of attitudes (Haddock & Zanna, 1998).

Stereotypical beliefs. The assessment of stereotypic beliefs has been central in the assessment of the cognitive component of attitudes towards minority groups. Stereotypic beliefs relate to the characteristics attributed to typical members of a target group, for example, the belief that group members are friendly or lazy. To measure stereotypic beliefs respondents were asked to write down words or phrases that 'came into their heads' when they thought about a person with Down syndrome then to evaluate each of these characteristics by allocating a valence (using plus or minus signs) to each response on a measurement scale. The valence is the degree of favourability with which the response is viewed and ranges from the very positive to the very negative (from +2 through to -2). A 'stereotypic belief score' was then computed by

summing the allocated valences and dividing this value by the number of responses. A range of example responses, generated from an earlier exercise were provided (Bryant, 2003).

Parental Quality of Life beliefs (PQoL). Previous research has suggested that measuring only stereotypical beliefs may not access important cognitions relevant to attitudes towards minority groups. Symbolic beliefs about how members of the group threaten or promote cherished norms, for example, ‘family values’ have also been shown to be important attitude components (Esses & Beaufoy, 1994). An earlier study (Bryant, Green, & Hewison, 2006) had demonstrated that beliefs about how a child with Down syndrome would affect parents’ lives discriminated between groups in terms of testing and termination intentions. In addition, values placed on life-goals such as ‘success’, ‘pleasure’ and ‘relaxation’ have also been shown to significantly relate to hypothetical intentions to test and terminate for conditions associated with learning difficulty (Evers-Kiebooms, Denayer, Decruyenaere, & van den Berghe, 1993). Respondents were therefore asked to write down the things that were most important to them in their life and to evaluate how each valued life aspect would be affected by having a baby with Down syndrome by assigning a valence from +2 through to -2. These cognitions were labelled Parental Quality of Life (PQoL) beliefs. The term ‘quality of life’ refers to a subjective experience of well-being and life satisfaction, that encompasses physical well being, material well being, social well being, and productive well being (Felce & Perry, 1997). PQoL beliefs were defined as beliefs that having a child with Down syndrome would ‘promote or threaten’ valued aspects of the respondent’s life. For example, a person may value their relationship with a partner and believe that having a child with Down syndrome would ‘put pressure on’ (threaten) this relationship, alternatively, a person might believe that having a child with Down syndrome would ‘strengthen’ (promote) their relationship. A PQoL score was computed as described previously. A range of example responses, generated from an earlier exercise were provided (Bryant, 2003).

Emotions. The affective component of the measures considers the emotions that members of the target group elicit in respondents. For example, a typical group member might elicit fear, admiration or both. Research shows that emotions contribute to the prediction of attitudes over and above the amount predicted by cognitive measures alone (Haddock & Zanna, 1998). Respondents were asked to list the feelings they experienced when they saw, met, or thought about a person with Down syndrome. They were asked to give

each feeling an evaluative rating from ‘very positive’ to ‘very negative’ (from +2 through to -2). An ‘emotion score’ was computed as described previously. A range of example responses, generated from an earlier exercise were provided (Bryant, 2003).

Experiences. Behavioural attitude information in terms of past experiences with the target group has been found to uniquely contribute to the prediction of inter-group attitudes over and above cognitive and affective information (Haddock, Zanna, & Esses, 1993; Haddock et al., 1994). The open-ended measures consider evaluations of experiences, that is, their ‘quality’ rather than the frequency. Respondents were asked to think about any experiences they had had of people with Down syndrome and to write down as many or as few experiences as they wanted to. They were encouraged to include those experiences that ‘stood out most strongly’ in their minds and then to evaluate each experience on a scale of ‘very positive’ to ‘very negative’ (from +2 through to -2). An ‘experience score’ was computed as described previously.

Eight pregnant women were interviewed to establish whether it was feasible to ask women to spontaneously generate the stereotypical beliefs, PQoL beliefs, emotions, and experiences associated with people with Down syndrome. All interviewees were white European, had a mean age of 27 years (range 18 to 36 years) and a mean gestation of 12.5 weeks. Four women had had at least one previous successful pregnancy. The interviews lasted an average of 30 minutes and were all transcribed by the researcher. No difficulties were encountered in terms of women generating the required responses. Following this, the full measures were piloted on 15 pregnant women (mean age of 27.5 years, mean age at leaving education was 16.9 years). A number of minor changes to wording and layout were made during the pilot phase.

Analysis

Data were analysed using the Statistical Package for the Social Sciences. Categorical data were analysed mainly using the chi-square test (χ^2) for independence of variables. Likelihood ratio tests were used where cell numbers were small as they are less sensitive to small sample sizes. Comparisons of group means were carried out using t-tests and one-way ANOVAs. Where assumptions of normality and homogeneity of variance were not met non-parametric Mann-Whitney tests or Kruskal-Wallis tests were used instead. Post-hoc Scheffe tests were used following ANOVAs to identify specific differences between groups. Bivariate

correlations were carried out using mainly Spearman's rank correlation test due to the non-normal distribution of many of the dependent variables, and for this reason also, binary logistic regression was selected to identify predictive relationships. The alpha level for all statistical tests was set at $p=0.05$.

RESULTS

Sample characteristics

Participants ranged in age from 18 to 43 years (mean 27.3, SD 5.5). Gestation at the time of returning the questionnaires ranged from 8 to 22 weeks (mean 13.2 weeks, SD 2.5). For 42% of participants this was their first pregnancy a percentage in line with the UK national average of 41% at the time of the study (National Statistics, 2002) The majority of the sample (75%) gave their religion as Church of England or other Christian denomination and the remaining 25% said they had, or gave no, religious affiliation. All participants described themselves as White with the exception of one woman who described her ethnic origin as Chinese. Table 1 shows some of the known socio-demographic variables of the population for the city where the study was conducted compared with the characteristics of the study sample. On this basis, and despite the low response rate, the participants were considered representative of the local population of pregnant women.

Attitudes towards people with Down syndrome

The following data were collated from the responses to the open-ended measures of attitudes towards people with Down syndrome.

Experiences. Experiences with people with Down syndrome were reported and evaluated by 160 participants (81%). Most of the experiences (87%) were reported to have been gained through some form of direct contact with individuals with Down syndrome, for example work situations or a family member with the condition. Twenty-one people reported having someone in their extended family with Down syndrome (11% of the sample overall) and this apparently high rate is considered further in the discussion. The remainder of reported experiences were gained via indirect sources, for example, watching a television programme.

Stereotypic beliefs. Stereotypic beliefs about people with Down syndrome were reported and evaluated by 163 participants (83%). The most frequently expressed beliefs related to the personality of people with Down syndrome; 59% expressed a belief that people with Down syndrome are ‘loving’ and 45% that they are ‘friendly’. ‘Learning problems’ or a similar phrase was recorded by 35% of participants and medical problems associated with Down syndrome were referred to by 11%.

Affect. Emotions associated with people with Down syndrome were reported and evaluated by 163 participants (83%). The most frequent emotions expressed were feelings of sympathy or pity for people with Down syndrome (47%). Sadness was the second most common feeling (36%), followed by feelings of protectiveness (20%).

Parental Quality of Life (PQoL) beliefs (symbolic beliefs about how having a child with Down syndrome would impact on valued aspects of parental life). The PQoL component was completed by 156 participants (79%). The most frequently reported valued life aspect was ‘family’ (57%), followed by ‘relationship with partner or husband’ (55%), ‘physical health’ (42%), and ‘existing children’ (39%).

Of the total sample, 71% participants completed all measures correctly and in full (n=140), 21% completed at least one of the measures incorrectly and 8% left the open-ended measures completely blank. The women who completed all the measures correctly differed significantly from those who did not only in their level of education: 21% of those who completed in full reported having some form of education beyond the age of 18, compared with 6% of those who did not complete in full ($\chi^2 = 9.5$, $df = 2$, $p < 0.01$). For the 140 women who completed the measures in full, the range of scores for each of the four attitude components was -2 to +2 and the range of overall attitude scores was -1.75 to +2 (mean +0.15, SD 0.7). The mean evaluation of experiences with people with Down syndrome came out positively overall (mean +0.55, SD 0.9) as did stereotypic beliefs about affected individuals (mean +0.27, SD 0.8). In contrast, emotions associated with thinking about or seeing people with Down syndrome were evaluated negatively overall (mean -0.09, SD 0.9) and the perceived impact of a child with Down syndrome on parental quality of life was viewed less favourably still (mean -0.31, SD (0.8).

Participant age correlated significantly and negatively with the experiences score ($\rho = -0.23, p < 0.05$), stereotypic beliefs score ($\rho = -0.31, p < 0.001$), emotions score, ($\rho = -0.18, p < 0.05$), PQoL beliefs score ($\rho = -0.27, p < 0.01$), and overall attitude score ($\rho = -0.31, p < 0.01$). Thus older women tended to hold the least favourable attitudes towards people with Down syndrome. None of the attitude scores showed any significant relationships with any other socio-demographic or obstetric variable, including education level, religiosity, gestation or parity.

Attitude towards having a baby with Down syndrome

Women were asked to evaluate 'having a baby with Down syndrome' on a scale ranging from 1 (extremely bad) to 9 (extremely good). Although the range of scores was 1 to 9 the modal response was 1 (extremely bad). Of the 195 women who responded to this item, 76% evaluated having a child with Down syndrome as 'bad' to some degree (a score from 1 to 4), 21% gave a mid-range response of 5 (neither good nor bad) and 3% evaluated the event as 'good' (a score of 6 to 9). Figure 1 shows the distribution of evaluation scores.

There was a modest but significant negative correlation between the age of the participant and their evaluation response ($\rho = -0.18, p < 0.05$), with older women viewing having a baby with Down syndrome less favourably in the main. No other socio-demographic or obstetric variable was associated with the evaluation variable.

Attitudes towards people with Down syndrome and an evaluation of having a baby with Down syndrome

All the 'attitude towards people with Down syndrome' component scores correlated significantly and positively with the evaluation of having a baby with Down syndrome at $p < 0.01$: Experiences ($\rho = +0.45$), Stereotypic beliefs ($\rho = +0.56$), Emotions ($\rho = +0.56$), and PQoL beliefs ($\rho = +0.68$). The overall attitude score also correlated significantly with this evaluation variable ($\rho = +0.70, p < 0.01$). A regression analysis was conducted to establish which attitude components best predicted the evaluation of having a baby with Down syndrome. As the distribution of the dependent variable was strongly skewed the evaluation variable was dichotomised and binary logistic regression was selected. The responses were separated into two categories using the following criterion; if having a baby with Down syndrome had been evaluated unfavourably (a response of 1 - 4), this was termed the 'Down syndrome not OK' category (DS Not OK); 106 women were in this category. All other responses, i.e. scores of 5 - 9 (neutral and favourable

evaluations) were placed in the 'Down syndrome Neutral/OK' category (DS Neutral/OK); 34 women were in this category. This was considered the best way to dichotomise the data as a median split would not accurately reflect the distribution of responses.

The attitude component variables were entered simultaneously into the regression model to establish the unique contribution of each component towards the prediction of the evaluation of having a baby with Down syndrome. Despite the unequal group sizes the goodness-of-fit test produced a non-significant chi-square value ($\chi^2 = 4.95$, $df = 8$, $p = 0.76$) indicating that the logistic model fitted the data at an acceptable level (Kinnear & Gray, 2000). The Nagelkerke R^2 value, which gives an approximation of the amount of variance accounted for by the predictor variables, was good at 47%. Of the four attitude components, only the Emotion and PQoL beliefs scores contributed significantly towards predicting the evaluation variable ($\beta = 0.79$ and $\beta = -1.23$, $p < 0.05$ and < 0.005 respectively). When the analysis was re-run with only Emotion and PQoL beliefs as variables these two attitudinal components were shown to predict 84% of cases correctly. Prediction was more accurate for the 'DS Not OK' category (93%) than for the 'DS Neutral/OK' category (53%). Thus an unfavourable attitude towards people with Down syndrome was better at predicting an unfavourable evaluation of having an affected baby, than a favourable attitude towards people with Down syndrome was at predicting a neutral or favourable evaluation of this event. For almost all participants – even those with favourable attitudes towards people with Down syndrome – having a baby with the condition was not seen as a 'good' outcome.

Intentions to use screening, amniocentesis and termination for Down syndrome

The response frequencies shown in Table 2 demonstrate that in line with previous work, more women hold positive intentions towards using prenatal testing than towards terminating a pregnancy affected by Down syndrome (Evers-Kiebooms et al., 1993; Green et al., 1993; Hewison et al., 2007). Of note is the very small number of women who gave a 'don't know' response to their screening intention, possibly suggesting that participants found the screening decision relatively unproblematic.

One-way ANOVAs revealed a significant difference in age between screening intention groups ($F(2,190) = 5.52$, $p < 0.01$). Post hoc tests revealed that age did not differentiate between the 'yes' and 'no' screening

intention groups but that women in the 'don't know' category were significantly younger than those who intended to have the test ($\rho = 0.05$). There was a non-significant trend for older women to be more likely to intend to use amniocentesis ($F(2,189) = 3.08, \rho = 0.052$) and women who intended to terminate for Down syndrome were older than the 'no' or 'don't know' groups ($F(2, 189) = 6.48, \rho < 0.01$). There were no significant relationships between religious affiliation and the intention variables although those participants whose religious upbringing affected their decisions 'quite a lot' ($n=5$) were significantly less likely to intend using screening, amniocentesis or to terminate for Down syndrome than other participants (Likelihood ratio = 11.7, 12.3, and 9.8 respectively, $df = 4, \rho < 0.05$).

Screening uptake

An overall serum screening uptake figure for the study period of 64% was obtained from the Immunoassay Laboratory at the hospital. In comparison, uptake for the 163 women whose records were available and permission for inspection had been given was 77%. Women who did not have serum screening were significantly younger than those who did have the test, at 25.4 years and 28.0 years respectively ($t=2.64, df=160, \rho < 0.005$). Screening intentions were good predictors of actual uptake behaviour. Excluding participants with reported gestations greater than 14 weeks ($n=34$) who may have expressed screening 'intentions' retrospectively, the proportion of women intending to use the test who did so was 89%. The proportion of women intending not to use the test who did not was 95%.

Attitude towards having a baby with Down syndrome by testing and termination intentions and screening uptake

Those women who intended to use screening, amniocentesis or termination evaluated having a baby with Down syndrome less favourably than those who did not (Kruskal-Wallis $\chi^2 = 25.3, 55.9$ and 105.7 respectively, $df = 2, \rho < 0.001$). This relationship was strongest in respect of screening intentions and weakest in respect of termination intentions. A similar pattern was observed when actual uptake figures were used; women who had used screening generally evaluated having a child with Down syndrome less favourably than those who did not have the test (Mann Whitney $U = 1131, N_A = 124, N_B = 38, \rho < 0.001$), however, 22 of the women who had a screening test were in the group who had evaluated having a baby with Down syndrome neutrally or favourably (a score of 5 or above).

Attitudes towards people with Down syndrome by testing and termination intentions

As screening intention was highly predictive of screening behaviour in this sample, the following analyses use screening intention rather than uptake to maximise inclusion of participants. For screening intentions, significant differences in attitudes towards people with Down syndrome were found only between the ‘Yes’ and ‘No’ groups. For the amniocentesis and termination intentions significant differences were found between all groups. The differences were all in the expected direction, that is, participants with the most favourable attitudes towards people with Down syndrome were least likely to intend to test and terminate and participants with the least favourable attitudes were most likely to intend to test and terminate. However, it is important to note that the mean attitude scores for women who intended to have screening was positive overall. ANOVA analyses revealed significant differences at $p < 0.05$ across all attitude components by intentions to have or not to have testing and termination for Down syndrome (see Table 3). Again, differences between groups were most marked in the ‘termination intention’ analyses with the ‘emotion’ and ‘PQoL’ components of the attitude towards people with Down syndrome consistently demonstrating the greatest ability to discriminate between groups.

To examine the variation in the strength of the different relationships more closely, participants were grouped into quartiles by their mean ‘attitude towards people with Down syndrome’ score. A comparison of intention responses of those in the first and fourth quartiles, i.e. those with the least favourable and the most favourable attitudes towards people with Down syndrome was conducted. Of those with the *least* favourable attitudes towards people with Down syndrome (mean attitude score -0.7, n=35), 94% intended to use screening, 83% intended to use amniocentesis, and 94% intended to terminate. Of those in the group with the *most* favourable attitudes towards people with Down syndrome (mean attitude score +1.1, n=35), 65% intended to have a screening test, 29% intended to use amniocentesis and 8% intended to terminate an affected pregnancy. Therefore, while holding an *unfavourable* attitude towards people with Down syndrome accurately predicted a favourable intention towards using screening, amniocentesis and termination holding a *favourable* attitude towards people with Down syndrome was not a good predictor of intentions *not to use* serum screening. However, a favourable attitude towards people with Down syndrome was a good predictor of intentions not to use amniocentesis and termination. This somewhat asymmetric pattern was confirmed

by the analysis of screening uptake by attitudes towards people with Down syndrome. Positive and negative predictive screening uptake values were calculated for the 'most favourable' and 'least favourable' attitude groups. The proportion of women in the 'least favourable' attitude group who used the screening test was 100%. The proportion of women in the 'most favourable' attitude group who did not use the test was 33%. In other words, 67% of those whose attitudes towards people with Down syndrome were the most favourable had a prenatal test to screen for the condition.

Qualitative data

Interviews were conducted with eight women at the start of the project as part of the development of the open-ended attitude measures. These interviews were never intended for full-scale qualitative analysis. However, when the analysis of the questionnaire data suggested that some women were separating their views about Down syndrome from their views about using serum screening, the interview transcripts were returned to. During the first four interviews, participants had said that in their view, information about Down syndrome was unnecessary at the screening stage but if further decisions regarding diagnostic testing had to be made they would 'need to know more'. This had seemed a surprising view and so the final four participants were directly asked: 'Does what you know about Down syndrome influence whether you have the triple-test or not?' The responses to this question were extracted from the transcripts and were as follows:

No. [I] would have the test anyway – any test is a good thing. (32 years, first pregnancy)

Yes. I've had positive experiences. I don't see it as such a bad thing if I had a handicapped child not such a bad thing, not the end of the world. (24 years, first pregnancy, intended to have screening)

No I'm not having the test because of that, not specifically just because it's Down syndrome. (36 years, sixth pregnancy)

No, it's not an influence. I just want to make sure that everything is OK. I just hope they don't find anything. It is a separate issue, Down syndrome and the test. (34 years, second pregnancy).

Although collected from a very small sample, these responses support the suggestion that women may separate their attitudes towards the target of prenatal testing from their attitudes towards the using testing. Some women undergo prenatal screening because, while they may 'hope for the best', they still refer to be prepared for the birth of a baby with a disability if that is going to be the outcome. Thirteen women in the

questionnaire sample who indicated that they would choose to have screening also said that this was to prepare for the birth of the baby rather than to facilitate termination.

DISCUSSION

The results of this study demonstrate that understanding a person's attitude towards a tested for condition and how they evaluate having a child with the condition may help predict their behavioural intentions regarding prenatal testing and termination. In particular, emotional associations and beliefs about how a child with Down syndrome may impact on valued aspects of parental life were significantly linked with an evaluation of having an affected child and intentions towards using prenatal tests and termination. This supports theories that the perceived costs and lack of rewards associated with parenting a child with a disability are important factors in prenatal testing choices (Lawson, 2006). However, while attitudes towards the condition might play an important role in the testing choices of some women this role is not necessarily consistent across all women, or across the different stages of the 'testing process'. In this study, attitudes towards people with Down syndrome were good predictors of intentions to terminate for the condition. In contrast, attitudes towards people with Down syndrome were weak predictors of intentions to use, and of actual use of, serum screening. An intention to undergo screening was reported in many women whose attitude towards people with Down syndrome was favourable and attitude towards termination for the condition was unfavourable. How might this be explained?

In British society – as in many others – having a child with a learning disability is viewed less favourably than having a child without a disability for a range of personal and social reasons (Lawson & Pierson, 2007). Most women hope for, and perhaps expect, a baby without a disability, and so compared to this outcome, any 'abnormality' is going to be at the very least disappointing if not distressing. Thus the majority of participants in this study indicated that having a baby with Down syndrome would be 'bad' to some degree. In this study around one quarter of participants said they would use screening to seek reassurance about the health of their child, an interpretation of the purpose of screening that has been demonstrated in many previous studies (Green et al., 2004; Shiloh, Eini, Ben-neria, & Sagi, 2001; Statham, 2002). However, while women hope for a healthy child, not all are willing to actively take steps to avoid having a baby with a disability. As in this study, some women have said they use prenatal testing as a way of being better prepared

for the birth of a disabled child (Press & Browner, 1997; Santalahti, Aro, Hemminki, Helenius, & Ryyanen, 1998). Research has also shown that some women make clear distinctions between people with a disability who are already born and those who are 'yet to be born', holding positive attitudes towards the rights of people with Down syndrome at the same time indicating they would prefer to prevent an affected child from being born (Bryant et al., 2006; Hashiloni-Dolev, 2006; Raz, 2004). For all these reasons, an unfavourable attitude towards having a child with Down syndrome is not incompatible with holding a favourable attitude towards people with the condition, and it is not necessarily paradoxical to hold both favourable attitudes towards using screening and unfavourable attitudes towards terminating an affected pregnancy.

A decision that is consistent with personal values is said to be one where the decision maker is aware of the value trade offs needed and selects the alternative that is consistent with their trade-off preference (O'Connor & O'Brien-Pallas, 1989). For those women demonstrating seemingly incompatible attitudes and behaviours the various values and attitudes surrounding Down syndrome and testing may well have been 'traded-off' with the resultant preference being for screening. It has been proposed that for attitudes to impact on behaviour they must first be activated and then be perceived as relevant guides to the behavioural options the individual faces (Snyder, 1982). If the individual does not believe that an attitude towards an object is a relevant guide, the attitude is unlikely to have much influence over that behaviour (Snyder & Kendzierski, 1982). Thus for some women, attitudes towards people with Down syndrome, or even having a baby with Down syndrome may not be activated at the screening stage because screening is separated from termination in their minds. When someone is thinking about whether they would abort a 'baby' with Down syndrome, attitudes towards the condition and the characteristics associated with that condition may appear to be directly relevant in a way that they may not be when thinking about undergoing screening. This would explain the greater consistency between attitudes towards people with Down syndrome and (hypothetical) intentions to terminate.

Fazio has also argued that attitudes based on direct experiences are more readily accessible from memory than attitudes based on indirect experience, with only accessible attitudes exerting direct control over behaviour (Fazio, 1989). Thus, if a person had a favourable attitude towards Down syndrome based on direct experience with an affected individual this is likely to influence their behaviour in an attitude consistent way.

According to this theory it would be more difficult to predict accurately the testing and termination intentions of someone whose attitude towards Down syndrome was based on indirect experience. In this study, although experiences were characterised as ‘direct’ and ‘indirect’ for descriptive purposes, this categorisation was subjectively based on self-reported qualitative responses, for example, ‘I have a cousin with Down syndrome’, and the level or frequency of contact was not measured. Therefore, Fazio’s theory was unable to be tested directly here. It may be hypothesised that the attitudes of women who have had a high degree of direct contact with people with Down syndrome would be better predictors of screening intentions than in those with less direct experience. However, it could also be argued that women with such direct experience of people with a condition may still want to use screening or diagnostic testing for reassurance and preparation purposes rather than to facilitate termination. This argument is supported by findings from a study of women who had a sibling with Down syndrome (Bryant, Green, & Hewison, 2005).

If attitudes towards having a screening test cannot be taken as a proxy for attitudes towards people with the condition, having a baby with the condition, or for terminating an affected pregnancy, this has implications for current conceptualisations of informed choice. The Multi-dimensional Measure of Informed Choice (MMIC) for example, is based on the TRA/TPB models (Marteau *et al.*, 2001). The TRA/TPB models were developed to help explain the relationship between how attitudes to behaving in a particular way link to actual behaviour. As such, attitude towards undergoing screening may well be a better predictor of screening behaviour than attitudes related to the tested-for condition or towards termination of pregnancy. However, as demonstrated in this study, an attitude towards undergoing a screening test may not be directly influenced by values associated with termination and disability, yet information that may result from undergoing screening can lead on to decisions regarding further invasive testing and termination. It is therefore argued that ‘attitude towards having a screening test’ is an overly narrow conceptualisation of ‘values’ in relation to informed choice for prenatal screening.

With this in mind, we can now consider whether or not it is of concern that attitudes towards the targets of prenatal testing may not be reflected in screening choices. In order to answer this question it is important again to consider the distinctions women seem to make between screening, prenatal diagnosis and termination decisions. Many participants did not view a screening test as a first step towards either

amniocentesis or termination supporting previous evidence that many women make clear distinctions between the purposes of screening and diagnostic testing and that the decisions they make about each are separately influenced (Browner & Press, 1995; Green et al., 1993). In the cases of the women interviewed at the beginning of this study, participants could be said to have displayed attitude-behaviour consistency if their attitude towards undergoing the test was favourable (for example, to gain reassurance) and they underwent screening. However, the apparent lack of association between undergoing a screening test and personal values in relation to people with the condition suggests a simple extrapolation from attitude-behaviour consistency to 'informed choice' in this case may be unwarranted.

If on the other hand a woman is well informed about Down syndrome (or other tested-for condition) and understands the limitations of the test along with the associated potential emotional and decisional consequences, then undergoing screening for preparation, reassurance, or knowledge purposes would seem to meet any definition of an informed choice. However, research shows that not all women are so well informed or engaged with the complexities of screening (Green *et al.*, 2004). As this study has demonstrated, many women do not have direct personal experiences of people with Down syndrome with which to inform their decisions and so will draw on experiences of disability in other contexts or vague perceptions of parenting a child with a disability (Etchegary *et al.*, 2008). Sometimes strongly expressed attitudes may not be 'informed' in any meaningful sense. One of the women interviewed during the development of the open-ended measures was very articulate in expressing her views of disability and her perceived inability to parent a child with Down syndrome. She also held highly favourable views of testing in pregnancy saying "I'm having every test that's totally possible". At the end of the interview the researcher asked if the participant had any questions, to which the interviewee responded,

"Yes, what is Down syndrome, do you know?" (21 years, fourth pregnancy)

In addition, the relatively weak association between attitudes towards people with Down syndrome – especially positive attitudes - and screening intentions and behaviour may be an indicator that other normative variables might play a more important role in the decisions of many. Attitudes towards undergoing a screening test may be strongly influenced by a generally shared desire to 'have a healthy baby', attitudes towards antenatal care or, in the case of nuchal screening, towards ultrasound scans which are almost universally popular with pregnant women. It is also likely that attitudes towards undergoing a test

may be influenced by information based on the values of others, such as advice or perceived recommendations from health professionals, the framing of the offer, or situational cues such as ‘opt out’ screening programmes or screening offered as part of routine appointments.

In relation to clinical practice, the findings suggest that the relevance of a woman’s personal knowledge and attitudes to prenatal testing decisions should be made clear at the screening stage. However, over-generalisation from a narrow range of personal experience might be counter-productive hence the continued need for development of accurate ‘balanced’ information accommodating a range of viewpoints (Ahmed, Bryant, & Hewison, 2007). Importantly, the findings provide further evidence that health professionals working in this field should not assume that a woman’s prenatal screening choice indicates any particular view on diagnostic testing or termination or draw conclusions about the person’s attitude toward people with the condition being tested for. Explicitly linking screening with diagnostic testing and termination is necessary if women are to understand the potential consequences of their screening tests. The screening information given to women at the study location did do this, but it is not known how many women in the study read – and understood - the information provided before making their screening decision. Constraints on clinic time may also mean that midwives do not have the time to discuss the implications of screening with women or ensure that women read the information material

Limitations of this study

It may be argued that the participants in this study were unrepresentative in a number of ways. Firstly, respondents to the survey appeared to hold somewhat more favourable views of using screening than the target population from which they were drawn. It is possible therefore that people who were more motivated to use screening were also more motivated to complete the questionnaire: this may reduce the generalisability of the findings of asymmetry between the attitude groups. Secondly, 11% reported having a person with Down syndrome in their extended family. It is not known how many people in the general population might be expected to have a family member with the condition but this sample is likely to have some level of over representation: the effects of this are unclear but they suggest some self-selection in terms of motivation to opt in to the study. Thirdly, those who completed the attitude measures had a higher level of education than those who did not suggesting the measures may have been more difficult to use than the pilot

and the literature suggested. The developers of the measures have argued that use of the open-ended format is not limited to populations with high verbal abilities (Esses & Maio, 2002; Haddock & Zanna, 1998). Despite this, there are few studies that have used the open-ended measures with non-student populations. The relatively low response rate also has to be considered. Although the reasons behind this are likely to be multiple the questionnaires were distributed by a third party (the midwifery team at the hospital) and as the numbers of returns decreased over the course of the study this suggests that fewer questionnaires were distributed as the project went along. The perceived difficulty of completing the open-ended measures may also have contributed to the relatively low response rate. Despite this, the lack of difference between those who fully completed the open-ended measures and those who did not on every other variable with the exception of education, suggests that a higher rate of completion would not have materially impacted on the findings. There were no significant differences between the two groups in terms of testing and termination intentions, attitudes towards people with Down syndrome or evaluation of having a baby with Down syndrome.

The role of attitudes towards the target condition in prenatal testing choices needs further exploration in a larger sample. However, it is argued that despite the acknowledged constraints on the generalisability of the findings to all pregnant women, the findings are sufficiently robust to suggest that attitudes towards the condition tested for may play a less important role in informing choices at the screening stage than has been previously thought. A recent Dutch study that explored influences on decision making in over 1500 pregnant women offered first trimester nuchal screening and serum screening also found that participants' perceptions of how bad or good having a child with Down syndrome would be for them was a weak predictor of screening uptake (van den Berg *et al.*, 2008). Although more work is required, significant progress towards early non-invasive prenatal diagnostic testing for Down syndrome is being made. Once the barrier of miscarriage risk is removed from prenatal diagnosis, decisions about the possible end points of a 'simple blood test' will need to come into sharper focus for many women. Non-invasive prenatal diagnostic testing has the potential to be offered routinely in the way prenatal screening tests currently are, at which point many more health professionals will need to engage in discussions about the 'ends' as well as the 'means' of prenatal testing.

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Table 1. Comparison of the characteristics of the target population and study sample

Variable	Target population	Study sample
Conception age	10% in women < 20 years ¹	9% of study sample < 20 years.
Age completed education	42% completed education at 16 ²	40% completed education at 16, 41% by 19, 16% > 19 years (3% gave no information)
Ethnicity	Largely white European.	All except one participant classed their ethnic group as White.

¹ (Peach, Harris, & Bielby, 1994);² (University of Hull, 2005)

Table 2. Intended use of screening, amniocentesis and termination: frequencies.

	Definitely/probably have %	Don't know %	Definitely/ Probably not have %
Screening ^{\$}	79	6	15
Amniocentesis (if positive screen*)	51	24	25
Termination (if positive diagnosis)*	46	28	26

^{\$} N=196, * N=195

Table 3. Attitude scores by screening, amniocentesis and termination intentions: means, standard deviations, and results of comparisons between groups (F values for one-way ANOVAs)

Screening Intention¹(n)	Experience (SD)	Stereotypes (SD)	Emotions (SD)	PQoL (SD)	Overall attitude (SD)
Yes (113)	0.5 (1.0)	0.2 (0.8)	0.0 (0.9)	-0.4 (0.8)	0.1 (0.7)
Don't know (6)	0.3 (0.8)	0.3 (0.5)	0.4 (0.8)	-0.3 (0.9)	0.2 (0.5)
No (18)	1.1 (0.7)	0.7 (0.7)	0.8 (0.9)	0.4 (0.7)	0.7 (0.6)
F (2, 134)	3.7*	3.3*	6.9**	9.0**	8.5**
Amniocentesis					
Intention (n)					
Yes (71)	0.3 (0.9)	0.0 (0.8)	-0.2 (0.9)	-0.7 (0.8)	-0.1 (0.6)
Don't know (31)	0.5 (0.8)	0.2 (0.6)	-0.1 (0.7)	-0.3 (0.7)	0.1 (0.5)
No (36)	1.2 (0.9)	0.7 (0.9)	0.7 (0.9)	0.3 (0.8)	0.7 (0.7)
F (2, 135)	12.4**	9.7**	13.1**	20.5**	23.5**
Termination					
Intention (n)					
Yes (62)	0.1 (0.9)	-0.2 (0.6)	-0.5 (0.7)	-0.9 (0.6)	-0.4 (0.5)
Don't know (38)	0.7 (0.8)	0.4 (0.6)	0.2 (0.7)	-0.1 (0.7)	0.3 (0.5)
No (39)	1.2 (0.8)	0.9 (0.8)	0.9 (0.8)	0.3 (0.7)	0.8 (0.6)
F (2, 136)	20.8**	30.8**	39.3**	44.9**	66.9**

* $p < 0.05$, ** $p < 0.001$; 1 Two participants who intended to bypass screening by having an early diagnostic test were excluded from these analyses.

Figure 1: Evaluation of having a baby with Down syndrome (N = 195)

